INTRODUCTION

The Centers for Medicare and Medicaid Services (CMS) granted New Jersey a Section 1115 Research and Demonstration Waiver to permit the state to implement Personal Preference: New Jersey's Cash and Counseling Demonstration Project. Personal Preference provides the opportunity for consumer direction and control by Medicaid recipients receiving or needing personal care by offering cash grants and counseling services in lieu of providing traditional agency personal care services.

As the State agency authorized to administer the Medicaid program, the Department of Human Services, Division of Medical Assistance and Health Services (DHS/DMAHS) applied for and received the waiver to provide Personal Preference to adults with disabilities and the elderly. The Director of the Division of Medical Assistance and Health Services has delegated authority for administration of the Personal Preference Program to the New Jersey's Division of Disability Services (DDS), Department of Human Services. The following individuals are responsible for the planning, implementation and operation of the demonstration program:

Project Director: William A. B. Ditto, Director
Division of Disability Services

Project Manager: Carolyn M. Selick
Division of Disability Services

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Demonstration Staffing Plan

The following staff have been employed during the Demonstration. This staffing plan covers only those staff who are assigned to work solely (100%) on the Personal Preference Program. Other Department of Human Services staff will devote time to the operation and administration of the program.

Program Manager:	Carolyn M. Selick
Coordinator of Counseling:	Renee S. Davidson
Coordinator of Enrollment:	Regis P. Hill
Support Specialist:	Patricia Della Vecchia

Goal of Personal Preference

The goal of the Personal Preference Program is to evaluate the efficiency and feasibility of a Medicaid personal care program option that offers consumer directed services through the provision of a monthly cash grant in lieu of traditional agency services. Mathematica Policy Research (MPR) independently evaluates the project. New Jersey program staff perform ongoing programmatic evaluations. The results of the study will provide a basis for future policy decisions with regard to the delivery of personal care services.

Sample Size and Characteristics

The targeted number of enrollees is 3,500 participants. Half are assigned to the treatment group and receive a cash benefit. The other half constitute the control group, which continue to receive traditional agency services. Half of the participants in each group are between the ages of 18 and 65 years and half are over age 65. Further, 30% of the participants are new recipients of personal care assistance and 70% have been receiving personal assistance services prior to enrollment in the Personal Preference Program.

PARTICIPANT ELIGIBILITY

Personal Preference is available to individuals who are receiving Medicaid personal care services or are eligible to receive Medicaid personal care services. New Jersey includes only those individuals who receive PCA as a Title XIX state plan service. Individuals must be 18 years of age or older and volunteer to participate after being informed about their rights, risks and responsibilities of managing their own services and cash grant.

New Jersey does not preclude any specific categories of clients from participation in the demonstration with the following three exceptions. Individuals whose need for PCA

services is estimated to be less than 180 calendar days, those beneficiaries who are receiving PCA (or PCA-like) services under our Medicaid 1915(c) Home and Community-Based Waivers or individuals who are eligible for Medicaid under the New Jersey Medically Needy Program. In order to assure the greatest possible degree of participation, the Personal Preference Program does allow participants assigned to the treatment (cash option) group to designate representatives to assist them in managing the cash grant where appropriate.

Payments to all caregivers (including family members) for services provided to the participant are treated as income for the caregiver and/or household where applicable. Cash grants received by participants are not counted as income or assets for individuals receiving Food Stamps, Supplemental Security Income, and HUD funds. Waivers have been negotiated and agreed to by these agencies.

Personal Preference assures non-discrimination and equal opportunity in compliance with all applicable State and Federal laws and regulations. Executive Orders and Civil Rights rules or regulations and the policies of the New Jersey Department of Human Services on Equal Opportunity and Affirmative Action are strictly observed.

PUBLICITY/PUBLIC RELATIONS

During the months prior to implementation, Personal Preference staff provided an overview of the project to potential participants, professional groups, interested community groups, DHS employees, advocacy groups, and others to promote interest in the project. This is expected to increase awareness and encourage eligible Medicaid beneficiaries to participate in the demonstration. Over 100 presentations have been completed by the time the demonstration is implemented.

Periodic public presentations and meetings have been conducted with the three home care industry associations active in New Jersey to make them aware of the program and to solicit their support. Dialogue is ongoing with these groups.

Public relations tools include a booklet, video, overhead transparencies, and an information sheet. Press releases about Personal Preference are available to local and statewide newspapers. Media announcements are coordinated with the DHS Office of Communications.

Various public service announcements (PSAs) have been developed in conjunction with the National Program Office and are circulated to radio and TV stations.

DEMONSTRATION ENROLLMENT PROCESS

The enrollment process for Personal Preference involves three phases; Intake, Marketing and Informed Consent. Following is an explanation of each phase.

Intake Phase of Enrollment

Currently, all individuals receiving personal care assistant (PCA) services have initial medical/social assessments and reassessments conducted by personal care assistant provider agency nurses, using a standardized assessment instrument. A registered professional nurse always does assessments and reassessments face-to-face with the client. The assessment tool used is a standard instrument used statewide since the fall of 1996. All PCA clients receive reassessments every 6 months, or more frequently, if there is a change in their condition.

Potential participants for the demonstration are initially seen by the traditional PCA provider agencies. When a PCA agency nurse conducts a clinical assessment on a new client, or a reassessment on a continuing client, the nurse completes and forwards to the state program office a Consumer Data Form. The form includes the client's name, address, and phone number, and the name and phone number of a relative, as well as the nurse's signature and name of the provider agency. The data form indicates the number of hours of PCA service the individual qualifies for. Directions for completing the Consumer Data Form, a supply of forms and a letter from the Director of the Medicaid program was initially distributed to all PCA Provider agencies in December 1998.

To insure that personal care needs are fully met during the enrollment phase, all individuals continue to receive services (or begin to receive services) from the traditional provider agency which conducted the assessment or reassessment while the enrollment and marketing activities are underway.

Within one week after the State Program Office (Division of Disability Services) receives a Consumer Data Form, an introductory letter and printed material on Personal Preference is mailed to the potential participant. The letter informs the individual that a representative of the state will contact them to discuss the program in greater detail. Concurrently, the State Program Office forwards information to the marketing/enrollment contractor including a calculation of the amount of the individual's cash grant.

A verification and review process conducted at the State Program Office screens out Consumer Data Forms on those individuals who require services for less than 180 days, are under 18 years of age, or are Medicaid 1915(c) waiver or Medically Needy eligible. The Enrollment Coordinator has access to the MMIS system and verifies Medicaid status. The data on these individuals is not sent to the marketing/enrollment contractor. Information on all potentially eligible participants is electronically transmitted to the contractor on a weekly basis.

New Jersey began enrollment when CMS approved this protocol and continues to enroll participants. The state needed to add participants to reach the target number of participants (3,500), therfore the enrollment period was extended beyond the planned year. Each participant receives the cash grant for up to two years after the date of enrollment.

The performance standard for this activity is to match claims from the Medicaid claims files against the data forms and lists submitted by the provider agencies. The Coordinator of Enrollment conducts this activity to assure that the forms are completed on each PCA recipient. Agency payment may be withheld in those instances in which an assessment has been billed to Medicaid but no data form has been received. This process is conducted monthly for the first six months of the demonstration and on a bimonthly basis thereafter.

Marketing Phase of Enrollment

MAXIMUS, a company that has previously contracted with New Jersey Medicaid to enroll beneficiaries in managed care and for other initiatives conducted marketing to individual consumers. This firm has a proven track record in working with Medicaid beneficiaries and agreed to partner with us for Personal Preference. The contract for marketing and enrollment activities began once this protocol was approved.

Within five (5) working days of receipt of the data from the Division of Disability Services on a potential participant, a MAXIMUS health benefit coordinator (marketer) conducts a telephone interview to explain the demonstration and secure agreement for a home visit. The potential participant is encouraged to have family members, friends and others present at the time of the home visit to help facilitate the marketing process. The health benefits coordinator can also contact a family member or other person listed on the Consumer Data Form to explain the demonstration when appropriate. The health benefits coordinator screens during the home visit to determine whether a representative is appropriate and/or necessary.

The home visit is conducted using a standard interview protocol and an outcome form is completed. Potential participants are carefully advised of the random 50/50 assignment process.

If the potential participant agrees to volunteer, the health benefits coordinator obtains a signed consent form and returns it to the Coordinator of Enrollment at the State Program Office. In those very rare instances where enrollment has been handled using the telephone without a home visit, the required signatures are obtained via mail.

The Coordinator of Enrollment electronically forwards names of consenting individuals to Mathematica Policy Research, Inc. (MPR) for random assignment. DDS staff also forwards a listing of all "refusers" to MPR on a weekly basis. Once random assignment has been completed, applicants receive written notice from the State Program Office regarding their assignment to the treatment or control group. This occurs within five (5) working days of receipt of randomization results from MPR.

MAXIMUS is required to report to the State Program Office's Enrollment Coordinator on a weekly basis regarding the outcome of each contact made to potential participants. The performance standard for completion of the home visit is ten (10) working days

following telephone contact. The result of the home visit is reported within two (2) working days to the Enrollment Coordinator, (for timely randomization at MPR).

Information is compiled on a monthly basis to review and evaluate the enrollment process. Information is collected regarding the enrollee to include county of residence, age, sex, race, living arrangements, use of representatives, relationship of representatives to participant, amount of grant, etc. Information is collected on individuals who refuse to enroll to include all of the above information and the reasons for refusing.

DDS staff make follow-up calls to a random selection of individuals who have been contacted by MAXIMUS to determine satisfaction with the marketing process and to learn of any difficulties or complaints.

Statistical data regarding the types of contacts, size of audience, positive and negative experiences, commonly asked questions, aspects of the project causing the greatest concern, and other related topics are gathered by the contractor monthly during the initial marketing phase and reported to DDS staff. Monthly meetings are conducted with MAXIMUS staff to assure that all of the Health Benefits Coordinators are presenting the specifics of Personal Preferences in a consistent and accurate manner and that any problems are resolved quickly.

MAXIMUS staff representatives participate; in the Continuous Quality Improvement Committee meetings conducted quarterly by the Personal Preference Program Manager.

Informed Consent Phase of Enrollment

At the time of enrollment, the participant/representative is asked to complete and sign a Consent Form. The form acknowledges voluntary participation in Personal Preference and awareness of, and acceptance of, the process of randomization. Consent also involves acknowledgement of how the delivery of personal care will be changed. Consent to release information to MPR is covered together with the assurance that personal information will be held in strictest confidence and that the release of evaluation data will not result in the identification of the individual participant. The consent form also addresses the issue of the potential impact of receipt of the cash grant on eligibility for other programs and services.

RANDOMIZATION

Data on individuals who have consented to participate is forwarded to Mathematica Policy Research within five (5) working days of receipt from MAXIMUS. Mathematica then completes a baseline interview and randomly assigns participants to the treatment (cash option) or control (traditional agency service) group. State Program Office staff are notified by Mathematica of the results of random assignment within ten (10) days of randomization.

The New Jersey Department of Human Services and the Division of Disability Services have no role in randomization and cannot effect the results. Individuals are informed of the randomization process and the 50/50 chance of their placement in the control or treatment group and asked for written acknowledgement of this at the time of enrollment. Enrollees may not appeal the outcome of the randomization process.

Control Group Assignment

After the Division of Disability Services receives notification of a participant's assignment to the control group, the participant is notified in writing. Control group participants are provided the toll-free number so that they may communicate any questions or concerns to the Personal Preference State Program staff.

The control group continues to receive personal care services in the traditional manner through an agency. Their clinical reassessments continue to be conducted by PCA provider agency nurses. They are asked and encouraged to participate in all research activities during the demonstration. As described in Mathematica documents regarding the research design, once an individual is assigned to the treatment or control group, that assignment continues for the entire demonstration. If the demonstration proves successful and is offered permanently under the Medicaid PCA Program, the control and treatment groups will be offered the opportunity to participate first.

Treatment (Cash Option) Group Assignment

All volunteers for the demonstration are notified of their assignment to the treatment (cash option) group within three working days of the Division’s notification by MPR. Once a participant has been assigned to the treatment group, they receive a letter from the Program Director with several enclosures. The enclosures are the Self-assessment/Decision Tree form and Cash Management Plan, which are included for the participant in anticipation of their first visit from the consultant. The Personal Preference Program toll free number is provided so that the participant can easily communicate any questions or concerns to program staff.

Participants who are assigned to the treatment group are able to be active participants in the Personal Preference Program for a minimum of 24 months. The period begins on the day of randomization.

To insure that personal care needs are met, all demonstration participants assigned to the treatment group receive services from the traditional provider agencies for up to three months (or 90 days) while they develop their Cash Management Plan and arrange for services. Once enrolled in the demonstration, participants in the treatment group have their reassessments conducted by registered nurses that are not employed by PCA provider agencies.

Once the Cash Management Plan has been created, reviewed and approved by the State Program Office, the personal care agency providing traditional services is notified in writing of the participant's assignment to the treatment group and advised of the date that agency services must be discontinued, if the participant has not elected to purchase service from the provider agency. If the participant has decided to purchase some services from a traditional provider agency, the participant makes arrangements directly with the agency and pays the agency with funds from their cash grant, with assistance from their consultant and the FISO as necessary.

PARTICIPANTS

Individuals meeting participant eligibility requirements may enroll. Participants must be over eighteen years of age and eligible for or receiving personal care assistance and in need of such services for at least six months. The participant and/or representative must also give informed consent to participate. Following randomization, those in the treatment group will select a Personal Preference consultant (counselor). Telephone and personal contacts will determine the individual's ability to understand the risks, rights, and responsibilities of managing their own personal care with the monthly cash grant. Individuals will be encouraged to complete a Self Assessment form and required to complete a Cash Management: Plan with the help of their Personal Preference consultant. This helps to assure that they are able to direct their own care. Individuals who are not comfortable with this responsibility or who are determined to be unable to understand this responsibility, are asked to identify a willing representative decision maker who is able to understand the risks, rights and responsibilities of managing personal care with a cash grant.

REPRESENTATIVES

A representative may be a participant's legal guardian, a family member, or any other individual identified who willingly accepts responsibility for performing cash management tasks that the participant is unable to perform. A representative must evidence a personal commitment to the participant and must be willing to follow their wishes and respect their preferences while using sound judgment to act on their behalf. Representatives receive no monetary compensation for this service.

Specifically, the representative must be willing to:

- Work with the Personal Preference Consultant to provide information to develop the Cash Management Plan on the participant's behalf.

- Use the cash grant for the items outlined in the Cash Management Plan as the participant wishes.

- Maintain records, as required by the State, regarding expenditures and activity with the fiscal intermediary service organization.

New Jersey prohibits representatives from paying themselves as an employee of the individual for whom they serve as a representative. To permit this would result in a clear conflict of interest for the representative.

Representatives may be desirable and/or necessary for participants under certain circumstances. These conditions are defined and procedures for establishing a representative arrangement are as follows:

Predetermined Representative

When a participant already has a legal guardian or other court appointed representative, the designated representative is given a Representative Description to review and the consultant or marketer completes the Representative Screening Questionnaire. The designee then completes and signs the Designation of Authorized Representative Form and indicates that the are the court-appointed representative. A copy is maintained in the participant file and the original forwarded to the State Program Office. The court appointed representative may choose to delegate this responsibility to another person, but that person can not be a paid caregiver.

Voluntary Representative

When a consultant determines that a representative is necessary for a participant to be successful, and the participant agrees, the potential representative is identified and given the Representative Description to review. The consultant interviews the potential representative and completes the Representative Screening Questionnaire. If the potential representative volunteers to serve, then the Designation of Authorized Representative Form is signed and witnessed. A copy is maintained in the participant file and the original forwarded to the State Program Office.

If the participant cannot identify a person to serve as their representative, the consultant is instructed to call the Coordinator of Counseling at the State Program Office for advice.

Mandated Representative

In those circumstances where the participant has misspent the cash benefit or their functioning has deteriorated in such a way that they are no longer able to manage the cash benefit independently a representative is required. The consultant will advise the participant that they are notifying the State Program Office of the need for a representative. The consultant will ascertain whether or not the participant is in agreement and then notify the Coordinator of Counseling at the State Program Office immediately. The Program Manager and Coordinator of Counseling then conferences and reviews the consultant's participant file. A home visit is made to the participant to determine whether or not an agreement can be reached. In those instances where a participant refuses to accept the designation of a representative and is not adhering to the policies of the program, the State Program Office retains the right to withdraw the

individual and make arrangements for them to return to the traditional PCA service. The participant is advised in writing of the decision and their right to appeal.

ROLE OF TRADITIONAL PERSONAL CARE PROVIDER AGENCY

Personal care provider agency staff are informed of the Personal Preference Program philosophy and the importance of the evaluation component of the demonstration. They are cautioned not to increase/decrease services due to the Personal Preference Program. The routine. quality assurance reviews currently conducted by the Medical Assistance Customer Center (MACC) staff permit a random review of case files to assure that inappropriate change of service hours, as a routine practice does not exist. Retraining of MACC staff regarding the details of Personal Preference occur as needed and are part of the orientation of all newly hired Medicaid staff. Their role in the demonstration is very limited.

MONTHLY CASH GRANT

The monthly cash grant is claimed from the Medicaid fiscal agent, Unisys, by the Personal Preference Program Fiscal Intermediary Service Organization (FISO).The FISO submits a claim form for each participant on a monthly basis. That disbursement is then deposited monthly (on the first workday of each month) by the FISO into the dedicated account for each participant. The procedure to determine the amount of the cash payment for each program participant is as follows:

The state uses the hours of service awarded to each individual from the initial assessment (or the reassessment) as the basis for the cash grant. The number of hours awarded is then translated into a dollar amount using the existing NJ Medicaid PCA reimbursement rates and reflecting whether the participant will be getting only weekday or both weekday and weekend services (rates vary in NJ). The base will be calculated this way for both current PCA clients and new enrollees.

New Jersey deducts ten percent for the cost of the counseling component and the cost of FISO functions. The remaining amount is available to the participant. If the individual opts to purchase services from the fiscal intermediary service organization (deducting payroll taxes for their employees and issuing payments to them, record keeping, etc.), the participant pays a modest transaction fee to the FISO from their cash grant for this service.

In New Jersey, the only Medicaid service to be replaced with a monthly cash grant is personal care assistant service. All other Medicaid services continue to be provided in the traditional manner. The cash grant is not discounted. This decision was reached after extensive research of Medicaid claims files conducted by program staff.

Determination of the Value of the Plan of Care:

Calculation of each participants monthly cash grant is completed using the following algebraic formula:

[(A+B)x4.33]x.9=C

A = the value of PCA received Monday through Friday each week, calculated by multiplying the number of service hours received by $15.50 per hour

B = the value of PCA received on Saturday, Sunday or a holiday each week, calculated by multiplying the number of (hours received by the rate of $16.00 per hour

4.33 weeks = the figure for calculating one calendar month

C = monthly cash grant to participant

These calculations are completed by the State Program Office staff and are reported to the health benefits coordinators when data are forwarded to MAXIMUS for marketing contact, so that potential participants are aware (before enrollment) of the actual amount of their cash grant. A study completed by program staff indicated no significant difference between the hours of service approved and the hours of service delivered under the existing traditional PCA program, so no discount factor is used in New Jersey.

The determination of the award of PCA hours is part of the assessment/reassessment process, which must occur at least every six months. Reassessment can also be triggered by any significant change in the client's physical condition or living arrangement. At the time of a reassessment, the value of the care plan is recalculated and the amount of the monthly grant adjusted accordingly.

USES OF CASH

Participants in the Personal Preference Program Treatment Group are offered a grant in lieu of traditional agency provided personal care. The intended use of the cash is to purchase personal care services, or technology, equipment or home modifications not otherwise reimbursed by Medicaid. Most uses of cash are outlined in the Cash Management Plan (CMP). However, up to 10% of the cash payment is considered discretionary and can be used without receipts, but with summary reporting to the assigned consultant. If the participant has a representative, all expenditures must be accounted for with receipts.

Following are examples of items that are permitted or not permitted under Personal Preference, for inclusion in the Cash Management Plan. These lists are not to be considered exhaustive. Each CMP is reviewed and approved on an individual basis by the State Program Office staff.

Items that are Allowable under the Personal Preferences Program:

- Employment of individuals, including family members, to provide care.
- Purchase of service from home care or temporary help agencies.
- Background checks and benefits for employees.
- Purchase or increase in rental or homeowner's insurance, or other liability insurance as it relates to participant's role as employer.
- Adult Social Day Care
- Caregiver training and education that enables the caregiver to deliver home care with high levels of quality. May be purchased from a variety of sources, including a home care agency or a vocational or technical school.
- Chore Services. This includes outside chores that provide for a safe environment and access in and out of the home.
- Cleaning Service from firms or individuals.
- Food preparation and delivery of prepared foods.
- Transportation services not currently paid for under Medicaid.
- Laundry service from a Laundromat or other provider.
- Errand service to assist with banking, shopping and other types of routine tasks.
- Home modifications such as ramps and grab bars, installation of visual or tactile alarms as well as wander alarms and other modifications not currently paid for by Medicaid.
- Respite services to relieve unpaid caregivers.
- Supplies and equipment that promote or enhance independence that are not currently paid for by Medicaid.
- Other items which can be directly linked to meeting personal care needs (subject to State Office review and approval)

Items Not Permitted under the Personal Preference Program:

- Food and/or beverages
- Entertainment equipment or supplies such as videos, VCR's, televisions, stereos CD's.
- Illegal drugs or alcohol
- Costs associated with travel (airfare, lodging, meals, etc.) for vacations or entertainment.
- Other items which are not directly related to meeting personal care needs

Savings

Cash from the monthly grant may be accumulated to purchase specific approved items that enhance independence. All funds (including savings) must be kept in an account separate from the participant's general funds and may not, at any time, be co-mingled with usual monthly income. Savings must be spent on appropriate items by the end of the demonstration period. Any savings retained by the participant after the demonstration will be declared a resource and may effect eligibility for other programs, i.e., food stamps, HUD housing, SSI, etc.

The Personal Preference Program cash grant is not to be considered as income to the participant. Any accumulated Personal Preference Program cash funds is not considered as an asset for the participant during the demonstration period. However, should the participant employ a family member(s) residing with them as a service provider, the salary paid to that person will be considered income and any savings resulting from this salary could become an asset. This may affect the family's eligibility for some means tested programs.

Employees

The purpose of the monthly grant is to meet personal care needs. It is anticipated that most individuals will use their grants to employ individuals to assist them. Employees will be recruited, interviewed, hired, and managed by the participant and/or representative assigned to the Personal Preference Program treatment (cash option) group. Family members may serve as employees.

<u>Required criteria for employees include</u>:

- Be a US citizen or legal alien with approval to work in the US
- Have a valid Social Security Number

- Be 18 years of age or older

Recommended criteria include:

- Be able to communicate successfully with the participant/representative
- Sign a Work Agreement with the participant/representative
- Provide a reasonable number of personal and professional references
- Submit to a criminal background check, if requested

After an employee is selected, the participant/representative identifies the exact tasks to be completed by the worker and a work agreement is completed and signed by all involved. The employee and the participant/ representative, on a time sheet signed by both parties, documents the schedule of the worker. Salary payments are calculated from these timesheets.

COUNSELING COMPONENT

Consultant Services

The state conducted an open non-competitive Request for Proposals (RFP) to identify agencies who wish to provide counseling services. Each of the forty-five agencies that responded will have signed a Department of Human Services contract that outlines their payment for services and their responsibilities to the Division Office staff and participants. Medicaid PCA providers are not permitted to provide the counseling services because of the potential for conflict of interest and the issue of contamination of the research. The State purchases services on an "as needed" basis from any interested agency using staff who has completed the state-funded mandatory consultant training, provided by the Rutgers University School of Social Work. All individuals who complete this training are considered "certified C&C consultants" and are eligible to provide counseling services in this Demonstration. The Consultant Job Description includes details of the functions and educational requirements for this position. The counseling component has, at a minimum, three potential broad areas of involvement.

Consultants will be used to:

- Provide orientation, training, and consultation services to participants in the development of their individual Cash Management Plan.
- Provide supportive counseling services to participants in the areas of recruiting, hiring, training, and firing personal care assistants, provide referrals to other services when necessary, and assist individuals in identifying equipment, assistive technology, and other purchases which would reduce person dependent needs and increase independence.

- Interact with the fiscal intermediary service organization as necessary to discuss issues related to the participants they serve.

A consultant may not serve more than 60 Personal Preference Program participants/representatives at any one time. To date, 100+ consultants have been trained and certified. We therefore have the capacity to serve more than six thousand participants. Additional training sessions will be offered in the future as needed.

Neither the consultant, nor counseling agencies, serve as a fiscal intermediary service organization.

Consultant Functions

1. Orientation and Training

Orientation on consumer-direction and Personal Preference is presented in a manner easily understood by the participant/representative and may be provided in small groups when appropriate. Orientation determines the knowledge the participant/representative possesses on employer issues, so that required training can be provided on recruiting, interviewing, hiring, supervising, evaluating and terminating assistants. A consumer manual is provided with written reference material on employer issues. Orientation sessions are also used to assess the participant's/representative's ability to self-direct and provide training and support.

2. Cash Management Plan (CMP)

The Cash Management Plan (CMP) is developed by each participant/representative and may be updated whenever needed. Consultants assist with this process. The CMP is intended to be a blueprint of how the monthly grant may be spent to meet the needs identified on the plan of care. The CMP may include a 10% discretionary amount, which may be spent by the participant without documentation. For reporting purposes, discretionary fund uses are self declared by the participant/representative and are a part of the quarterly reporting requirement. The CMP may also identify purchases or services needed that require some savings on a regular basis to purchase these items. Cash Management Plans must be reviewed and signed by the consultant. Consultants submit the plan to the State Program Office staff who provide final approval of the CMP. Consultants are notified by phone of the approval, followed by written notification. If a plan is not immediately approved the consultant will inform and assist the participant with revisions.

3. Work Agreements

The consultant will strongly suggest that a written work agreement be executed between the participant/representative and each of their employees. This agreement details the tasks, days and number of hours of service the participant/representative

and employees have agreed upon. Both the participant/representative and the employee is given a copy of this agreement to retain for their records.

4. Back Up Plans

The consultant assists the participant/representative in developing a back up plan to outline how the participant's needs will be met should there be an emergency situation where care can't be provided in the usual fashion. This plan is to be documented in the consultant narrative note. During quarterly contacts, the consultant will determine whether the backup plan has been used, and if so, how it worked.

5. Monitoring

It is the responsibility of the consultant to monitor the Cash Management Plan to the degree necessary to ensure that participation in the Project does not compromise the health and well being of the individual participant. During the initial three months of participation in the demonstration, the consultant interacts with new participants via telephone and home visits to develop an awareness of the participant's personal care needs and to assist in the development of the Cash Management Plan. During the first six months of participation in the demonstration, monthly telephone contact is required between the participant and the consultant. A face-to-face visit is required at least once each quarter for the monitoring purposes. The consultant must document all contact and activity related to the participant. The consultant also monitors the participant for any apparent changes in condition, which would necessitate a reassessment; the quality of the self-directed care; and to assure that needs identified in the Cash Management Plan are appropriately met.

6. Peer Networking

The Counseling Agency, through the consultant facilitates the opportunity for peer counseling and support among the participants and representatives they serve. This may include providing a meeting place, facilitating, and supporting peer group meetings on a regular basis. Another task may be referrals to other peer groups within their geographic area and collecting the names, addresses and telephone numbers of participants/ representatives who wish to be part of a peer network. Consultants may choose to produce a newsletter with articles by participants/representatives or articles written by others on issues important to the peer network. The agency and individual counselors are encouraged to be creative in assuring that participants/representatives have the support necessary for success.

7. Documentation

A record on each participant assigned to the consultant must be established and maintained. Each contact with the participant or representative should be documented in a summary/narrative note that includes discussion of back up plans when appropriate. Copies of all Cash Management Plans, completed Self-Assessment Forms,

Work Agreements, etc. should be maintained in the record. All monitoring contacts and telephone calls should be documented in narrative form or on a monitoring record.

8. Reporting

The consultant provides the State Program Office staff with documentation on individual participants/representatives they serve on demand. These records include information on any changes in conditions, quality of care received, and number and type of monitoring visits. Reports of problems, non-compliance with program requirements, misuse of the monthly grant, conflicts with participant/ representative and paid caregivers or others, abuse, neglect or any other significant occurrence will be reported immediately upon identification of the problem to the Division Office Staff. The Counseling Agency agrees to provide any additional reports upon request by Division Office staff. Specific documentation requirements are outlined in the Agreement of Understanding with each Counseling Agency. Consultants report monthly how many participants are being served, how many hours of training were provided, how many hours of consulting were provided, how many participants have representatives and what type, and any unusual problems or issues.

Participant's Use of Counseling Component

The participant/representative are provided with a list of agencies in their geographic area that have been approved to provide consultation services. They are asked to select the agency of their choice. In the event that a participant or representative does not wish to make a selection, the State Program Office will assign an agency. The counseling agency selected (or assigned) contacts the participant within five (5) days to set up an appointment and assists with the development of the Cash Management Plan as requested by the participant. Participants/representatives are expected to be sufficiently trained and ready to begin receiving the cash grant and to discontinue using traditional personal care services within 90 days of their referral to the counseling agency. If an extension of this limit is required, a request for an extension must be submitted to the State Program Office staff with appropriate justification for the delay. Extensions are granted in 15 day increments with no more than two (2) extensions permitted per client.

The initial appointment between the consultant and participant and/or representative focus on providing training and orientation to consumer directed services and the Personal Preference Program. Discussion of the Statement of Rights and Responsibilities Form is also covered, and necessary signatures are secured. Development of the Cash Management Plan, identifying the participant's service needs and uses of the cash to meet those needs are introduced during this visit. The participant/representative is given information about the fiscal intermediary service organization and the two options from which they may choose fiscal services. Subsequent contacts occur as requested by the participant or representative, but no less frequently than once each month. An aggregate of telephone contacts over a period of time may be counted as the monthly contact, but a face-to-face meeting must

occur at least quarterly. Travel time is not billable and cannot be used as part of contact time.

FISCAL INTERMEDIARY SERVICE ORGANIZATION COMPONENT

The single independent statewide entity serving as the Fiscal Intermediary Service Organization (FISO) is under contract to the state to handle various fiscal transactions for all participants in New Jersey. The company has the capability to perform financial transactions as the fiscal intermediary. A competitive request for proposal (RFP) process was used to select the FISO.

Each month the State Program Office staff, under the direction of the Director/Manager, provides the fiscal intermediary service organization with a list of individuals approved to receive cash grants and the dollar amount for the individual. The FISO, using a unique procedure code submits a claim electronically to the Medicaid fiscal agent, UNISYS. UNISYS then disburses the funding for each participant at the beginning of the month to the FISO. The fiscal intermediary service organization then deposits the grant in a segregated account for the participant, less 10% that is used by the State Program Office for administrative costs. These costs include the payments to counseling agencies for consultant services rendered, which is disbursed when invoices have been approved by the Program Manager or designee.

Options for Managing the Cash Grant

The participant has two options for receiving the cash grant:

Option One: The participant is set up a separate account for maintaining the cash payments. The participant receives disbursement for the entire amount of the cash grant once per month. All participants choosing this option are required to pass the Employer Skills Exam, developed and administered by the FISO, to assure that they understand all the responsibilities of becoming an employer. The FISO electronically deposits the monthly cash grant into the participant's account. In addition, the participant is expected to keep records which enable the consultant and FISO staff to reconcile cash grants with expenditures and assure that employees have been treated fairly in terms of taxes, withholding, etc. Specific responsibilities of the participants who chose Option One are outlined in the RFP, Section 2.1

Specific details regarding the FISO responsibilities to the participants in Option One are outlined in section 3.2.2 sand 3.2.4 of the RFP. Responsibilities of the FISO to the Division of Disability Services are outlined in Section 3.9.1 of the RFP as they relate to Option One participants.

Option Two: The participant directs the fiscal intermediary service organization to deposit the cash grant into an account (set up by the FISO) on a monthly basis. All participants must begin Personal Preference under this option, but may move to Option

One after successfully passing the Employer Skills Exam. Under this arrangement the participant "directs payments" as he or she sees fit. The fiscal intermediary service organization, upon the participant's authorization, handles payroll tax deductions and issues payment to the participant's employees. In addition, the client can request money be sent to them from the account (in accordance with their Cash Management Plan) to make purchases themselves or they can request that the intermediary issue a payment on their behalf. Under Option two, the fiscal intermediary service organization will deduct a transaction fee from the cash grant to cover the cost of all transactions, much as a bank deducts a monthly service charge. The FISO provides the participant with a detailed financial statement each month showing all payments and charges. Details of the responsibilities of the FISO to Option Two participants are outlined in the RFP section 3.2.3 and Section 3.9.2 covers the FISC responsibilities to the Division of Disability Services.

Functions of the Fiscal Intermediary Service Organization

1. Manual, Testing and Training

The FISO provides a manual and training for participants and develops and administers a skills test for those participants who choose to manage their cash benefit under Option One. The fiscal agent is available for consultation with the participant /representative as outlined in the RFP should questions or concerns arise. The FISO offers a voluntary training program for any consumer, or representative, who wishes to manage the cash grant and desires training prior to taking the examination. All participants have a consultant face-to-face interview every three months to review the expenditure of funds and determine how it compares to the original cash management plan. For those participants who are managing cash without assistance from the FISO (Option One), the FISO reviews revenue and expenditures with a random sampling of employer records of participants on a periodic basis and determines whether the participant has been making the correct deductions and payments for employees.

2. Payroll Functions

Option One: The participant is responsible for all payroll functions as the employer of record. The fiscal intermediary service organization, on behalf of the Division Office will randomly review records of participants in Option One as outlined in Section 3.2.2 of the RFP.

Option Two: The fiscal intermediary service organization performs all payroll functions as the participant directs. This procedure is detailed in the RFP Section 3.2.3 Savings Accounts.

3. Savings Accounts

Participants are permitted to accumulate cash for up to one year to purchase items or services contained within their Cash Management Plans. The fiscal intermediary service

organization may establish and maintain a savings account for individuals who do not spend all of a monthly grant on items related to personal care needs. Funds designated for savings are transferred to an interest bearing savings account as soon as all attendant salaries have been paid for the month or no later than the 5th day of the following month. These funds may be saved to purchase more expensive personal care items and withdrawals may be made from this account on a monthly basis to purchase appropriate items or services. As previously stated, these funds must be segregated from other accounts (as agreed to in the waivers with SSA, FNS, etc) to assure that they are not co-mingled with other funds and counted as assets.

At the end of each 12-month period, the consultant meets with the participant to determine if the accumulated cash is needed for the purchase of an item or additional service. If the cash is not needed for a purchase it will then be returned to the state. The monthly or annual amount spent by clients do not negatively impact future cash grants, unless the participant voluntarily agrees to reduce their grant. All savings must be spent on appropriate items by the end of the demonstration period.

4. Monitoring

The statewide fiscal intermediary service organization review a sample of related documents on a quarterly basis for the purpose of monitoring the performance of Option One participants. Specifically, they shall examine the management of the following for accuracy and timeliness: Payroll; associated income and employment tax; advanced earned income credit withholdings, deposits, and filings; preparation of form 1099-Misc. (when appropriate); and the payment of non-labor related invoices. However the FISO will not be required to certify that participants are in full compliance by completing this task. Rather, the task should be considered as ongoing technical assistance to Option One participants regarding these employer-related matters. The FISO shall report its findings to the Division Office quarterly, which will determine if any action needs to be taken

5. Reporting

The FISO complies with all established State Program Office monitoring schedules and requirements as outlined in the RFP for the FISO. Problems such as misuse of the funds, failure to pay assistants as required, failure to comply with applicable state and federal employer laws, failure to submit documentation of expenditures as required or other negative situations must be reported to the Division Office immediately.

REASSESSMENT

In the traditional PCA program, nursing reassessment is required not less than 6 months after the initial start of care date or whenever a significant change in condition occurs. A clinical reassessment is required to re-evaluate the client's needs. The reassessment will determine whether personal care continues to be required and if so, to determine the amount and frequency. PCA provider agency nurses normally perform

these reassessments. These reassessments are billed to Medicaid separately using a unique procedure code and are not part of the hourly reimbursement provided for PCA services.

Once enrolled in the demonstration, participants in the treatment (cash option) group have reassessments conducted by registered nurses that are not employed by PCA provider agencies. These nurses are employed by the State. This is obviously required in order to protect the integrity of the research. For those in the control group reassessments will continue to be conducted by PCA provider agency nurses.

For both groups, the reassessments of the need for personal care services must follow the established policy and procedure in the New Jersey Medicaid Manual for Personal Care Assistant Services, and be conducted using the same instrument to assure comparability.

The Treatment Group participant's six-month reassessments to be conducted by registered nurses (not employed by PCA agencies) will offer an opportunity for clinical quality assurance and outcome measurement. In addition to these activities, the NJ Medicaid District Offices routinely conduct quality assurance assessments of a sample of clients receiving personal care assistant services. A state-employed nurse or social worker completes a nine-page questionnaire during a home visit. This routine QA process will include individuals in the Personal Preference Program. The additional set of questions that the consultant will ask the participant will pertain to the subjective quality of services purchased through the demonstration and participant satisfaction.

Certification of Need for Care

A nurse employed by the State will complete treatment (cash option) group participants' reassessments. At that time a form letter will be sent to the individual's attending physician by the nurse explaining their patient's; involvement in the Personal Preference Program and requesting that they complete, sign and return the bottom of the letter to indicate that the participant still medically requires personal care assistance.

CHANGE IN PARTICIPANT STATUS

Each time a Treatment or Control Group participant is discharged from the demonstration, regardless of the reason, State Program Staff will notify Mathematica Policy Research.

Loss of Medicaid Eligibility

Participants must remain Medicaid eligible to continue participation in the Personal Preference Program. When the Division Office is notified that a participant has lost financial eligibility for Medicaid, the Coordinator of Enrollment notifies the Personal Preference consultant. The consultant assists the participant in determining whether (a)

the action to terminate is correct and (b) make referrals for continued services under another program where appropriate.

Loss of Medical Eligibility for Personal Care

If at any time, the personal care provider or the State Agency nurse determines that personal care is not medically necessary for a participant in the Control or Treatment Group, Division Office Staff will be notified.

Institutionalization

1. Hospitalization

A Personal Preference Program participant may be hospitalized for a continuous hospital stay of less than 5 days without interruption of their cash grant. However, for stays longer than five days, the cash grant will be prorated accordingly.

2. Nursing Facility Placement

If at any time a treatment group participant requires nursing facility placement, the consultant will notify the State Program Office Staff. Participants assigned to the treatment group are required to sign a Statement of Rights and Responsibilities that requires them to report any admission to a hospital, rehabilitation facility, or nursing home to their consultant within five days of the admission. No monthly grant will be provided during the time of institutionalization.

Move Out Of State

Should the Personal Preferences participant move out of the State of New Jersey, the participant, provider agency or the consultant must immediately notify the State Program Office staff. State Program Office staff will notify other involved state and federal agencies of the change of address.

Death

Should a Treatment or Control Group participant die, the personal care provider agency or the participant's family or consultant will notify Division Office Staff, who will notify MPR.

Transfer to Waiver Programs

Should a participant in the Personal Preference Program be accepted as a client in a Home and Community Based (1915c) Waiver Program, the participant is removed from the Personal Preference Program. Waiver clients are excluded from participation in the Personal Preference Program.

Voluntary Withdrawal

If a person already enrolled in the demonstration wishes to leave the program voluntarily, there is a mandatory consultant visit to assure that any problems are addressed. Every attempt is made to resolve the issues or concerns that the participant identifies as their reason(s) for withdrawing. The participant is encouraged to remain in the program. If that is not possible, the participant may withdraw at the end of the month and begin the next month in the traditional service model.

Temporary Absences from the Home

Personal Preference Program services, unlike Medicaid Personal Care, is designed for provision of services outside the participant's home as well as at home. The services may be provided outside the participant's home:, provided the participant does not leave the state for an extended period of time that would jeopardize their Medicaid eligibility.

Involuntary Termination

Participants assigned to the Treatment Group may be terminated for the following reasons:

• Change in Condition

Should the participant's ability to direct his or her own care diminish to a point where they can no longer do so and there is no appropriate representative available to direct the care, the participant will be returned to the traditional program.

• Misuse of Grant

Should the participant or the representative use the grant to purchase items unrelated to personal care needs, fail to pay the salary of an employee, or fail to pay related state and federal payroll taxes, the participant/representative will receive a warning notice that such exceptions to the conditions of participation are not allowed. The participant is permitted to remain on the program, but will be reassigned to Option Two. The participant/ representative is notified that further failure to follow the expenditure plan could result in involuntary termination from Personal Preference. Should an unapproved expenditure or oversight occur a second time, the participant/representative is notified that their participation in Personal Preference is terminated and they are being returned to traditional personal care.

• Failure to Provide Required Documentation

Should the participant/representative fail to provide required documentation of expenditures as requested, the participant will be returned to Option Two. If the participant refuses, they are terminated from Personal Preference and return to traditional personal care.

Cash Grant Recovery

In the event that the Fiscal intermediary service organization incorrectly makes a cash payment to the participant/representative, it is the responsibility of the Fiscal intermediary service organization to recover funds. If the suspension was temporary, the amount of money to be recovered will be deducted from the next advance payment. If the payment was made to a participant whose care is closed, the FISO will send a letter to the participant/representative requesting that the money be returned.

Regardless of the outcome of the recovery efforts of the FISO, for any management fee paid to the FISO for a period in which the participant was ineligible for the monthly grant, the FISO makes repayment to the State.

APPEALS

The Hearings and Appeal process established by DHS for Medicaid clients and an internal administrative review process established for Personal Preference participants by State Program Administrators will protect the rights of participants. Administrative Reviews were developed for this program to afford the participant or representative a timely review for issues not addressed by Fair Hearings and Appeals. An Administrative Review may be requested in writing or by telephone and a decision will be made within ten (10) working days of receipt at the Division Office.

Loss of Medicaid Eligibility

The participant may file for a Fair Hearing and appeals within 20 days from the date of notification of closure as outlined in the DHS/DMAHS Policy.

Loss of Eligibility for Personal Care

The participant may file for a Fair Hearing and appeals within 20 days from the date of notification of closure as outlined in the DHS/DMAHS Policy.

Involuntary Withdrawal / Refusal of Representative

The participant/representative has 20 days from the date of notification of disenrollment to file an administrative review of this decision. Administrative Review requests may be mailed or phoned to Division Office staff and must be postmarked or received within 20 days of the termination decision. All notifications of Involuntary Termination must be made in writing and sent by Certified Mail with a Receipt to assure that the date the notification was received is documented. Requests received after this 20-day limit will not be reviewed. Reviews will be completed and decisions will be available within 20 days of the request.

Dissatisfaction with the Number of Personal Care Hours on the Plan of Care

If the participant feels that the number of hours of personal care identified on the Plan of Care is inadequate, they may request a re-Evaluation by a nurse not involved in the original determination. In the event that the participant is still dissatisfied, following the second evaluation, no further appeal is available.

Randomization to the Control Group

No appeal is available, as this is not a function of the State agency, but a consequence of the research design of the demonstration.

Complaints Regarding MAXIMUS, the Counseling Agency/Consultant or the Fiscal Intermediary Service Organization

If the participant is dissatisfied with any service provided by the Consultant, Fiscal intermediary service organization, or MAXIMUS they may call the Division Office toll-free number, 1-888-285-3036, to discuss the problem with Personal Preference Program Staff.

PARTICIPANT FREEDOM OF CHOICE

Each participant retains full freedom of choice while in the demonstration. Participants in either the control or treatment may change providers at any time. Participants in the treatment (cash option) group may hire whomever he or she chooses, and make contract with any agency or firm to provide personal care and personal care-related services.

The participant is offered their choice of counseling agency. After selection they are also permitted to request a change of consultant, or counseling agency, with reason. If the participant is unable or unwilling to choose a counseling agency, they may allow their representative to choose for them. If no representative is available to make a choice, the participant will be assigned to a counseling agency on an "auto-assign" basis.

PARTICIPANT RELEASE OF INFORMATION

The confidentiality of all participant records and transactions in accordance with federal and state laws is assured. No information regarding specific participants or representatives will be disclosed except for purposes directly connected with the operation of this project. Specific informed, written consent will be obtained for any disclosures.

The participant extends his/her written consent to a limited release medical and/or social information when they sign the Personal Preference Consent Form.

REPORTING OF ABUSE

New Jersey law does not mandate reporting of suspected neglect or abuse of adults. However, consultants trained for the Personal Preference Program are required to report suspicions to the Division staff and will be encouraged to report to their County Offices of Adult Protective Services, if they have reasonable cause to suspect that an adult has been abused or neglected.

A report of abuse, neglect or exploitation of an endangered adult residing in a privately owned or rented home in the community shall be made to the New Jersey Department of Health and Senior Services (APS). The APS toll-free telephone number is 1-800-792-8820. If consultants report to Division Office staff but not to Adult Protective Services, then Division Staff will report to the above State Agency.